



Australian Government
National Health and Medical Research Council



Chair
Community Affairs Legislation Committee
c/- Committee Secretary
Senate Standing Committees on Community Affairs

via email: community.affairs.sen@aph.gov.au

Dear Chair

RE: Inquiry into equitable access to diagnosis and treatment for individuals with rare and less common cancers, including neuroendocrine cancer.

The National Health and Medical Research Council (NHMRC) welcomes the opportunity to provide a submission to the above enquiry. This submission addresses the term of reference *d) the adequacy of Commonwealth funding for research into rare, less common and neuroendocrine cancer.*

NHMRC

The National Health and Medical Research Council (NHMRC) is the Australian Government's lead agency for funding health and medical research. We invest in the creation of new knowledge about the origins, prevention, diagnosis and treatment of disease, drive the translation of health and medical research into evidence-based health practice and policy and provide guidance on responsible research practices and ethical issues that fosters the highest standard of ethics, quality and integrity in health and medical research.

NHMRC is an independent statutory agency within the Health Portfolio and operates under the *National Health and Medical Research Council Act 1992* (the NHMRC Act). It comprises the CEO, the Council of NHMRC, Principal Committees and its staff. The CEO of NHMRC is advised and supported by the Council of NHMRC, and assisted by a number of Principal Committees. The Council represents a wide range of expertise. Currently chaired by Professor Caroline Homer, it includes the Australian Government Chief Medical Officer and state and territory chief health and medical officers. It also includes members with specific expertise in health and medical research, the health needs of Aboriginal and Torres Strait Islander peoples, consumer issues and business.

Principal Committees assist Council in carrying out its functions, helping to provide an effective governance and advisory structure for NHMRC. The establishment of the Research Committee (RC) is required by the NHMRC Act and its functions are determined by legislation. The role of RC includes advising Council on the application and monitoring of the Medical Research Endowment Account (MREA) and on matters relating to medical research and public health research, including the quality and scope of such research in Australia.

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NHMRC's health priorities

The NHMRC Act requires the CEO to identify major national health issues likely to arise. The major national health issues identified by the NHMRC CEO as priorities for NHMRC for the current triennium (1 July 2021–30 June 2024) are:

- strengthening resilience to emerging health threats and emergencies, including environmental change, pandemics and antimicrobial resistance
- improving the health of Aboriginal and Torres Strait Islander people including through research that addresses health inequities
- building capacity and innovation in the effective translation of research into quality health policy, services and care
- preventing and managing multimorbidity and chronic conditions
- identifying emerging technologies in health and medical research and in health care, and promoting their safe, ethical and effective application.

In considering these issues, the CEO consults with the Council, its committees and the Minister, and considers the role of NHMRC within Australia's health and medical research landscape, before determining the issues that are within NHMRC's scope.

NHMRC's longstanding approach is to deliver funding that builds the foundations of the national health and medical research system — high-quality research along the pipeline from discovery to implementation; an excellent biomedical, clinical, public health and health systems research workforce; national and international partnerships between disciplines and with the community, health providers and industry. Through a mix of investigator-initiated and targeted research, NHMRC supports research across the broad range of health and medical needs.

Accordingly, NHMRC's health priorities reflect broad health challenges and emerging issues where national capacity or capability in health and medical research is most needed, rather than specific diseases. They also reflect areas where NHMRC's role in promoting the highest standards in health research and care can contribute to addressing major national health issues likely to arise.

NHMRC's approach to funding

As the largest single funder of health and medical research in Australia, NHMRC provides leadership and direction for the national health and medical research agenda. As a national body, NHMRC has a responsibility to cover the breadth of health and medical research needs. NHMRC distributes grants through a range of schemes with specific aims, e.g., to create knowledge, to build capability, to accelerate translation of research findings into policy and practice, to foster collaboration, to strengthen international research links and to build partnerships with industry, policy makers and other research users. Encouraging international collaboration is important for disease areas such as rare and less common cancers, to increase the critical mass needed for research progression.



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Consistent with the NHMRC Act, NHMRC focuses on the relevance of research proposals for health, rather than defining 'health and medical research' as a set of research disciplines. NHMRC will fund research in any or all areas relevant to health. It will also accept grant applications in any research discipline and applicants are provided with an opportunity within their application to explain how their research will lead to improved outcomes in health.

NHMRC does not generally determine the subject of research grant applications. Most NHMRC funding is awarded in response to investigator-initiated applications in which the research is proposed by the researchers in the application to NHMRC, based on the expertise and research interests of the applicants. A smaller proportion of funding is directed to specific areas of unmet need, e.g., through Targeted Calls for Research and international collaborative schemes.

The primary criterion for all funding decisions is excellence. NHMRC relies on review by independent experts to identify the best applications, based on the significance of the research, the quality and feasibility of the research proposal, and the track record of the investigators. Rigorous processes of expert review ensure transparency, probity and fairness.

When applications for funding are received, the office of NHMRC manages the expert assessment of applications by independent experts. The outcomes of expert review are used to determine which applications will be recommended for funding. NHMRC's RC recommends those applications to be funded through NHMRC Council to the CEO who submits them for approval to the Minister with portfolio responsibility for NHMRC.

Data on NHMRC-funded research

For the purposes of this submission, NHMRC has presented research funding for rare and less common cancers from 2018-2022 at [Attachment A](#).

This submission used the AIHW definition of 'rare cancers' (those with incidence rates lower than 6 cases per 100,000 people) and 'less common cancers' (those with incidence rates between 6 and 12 cases per 100,000 people).¹ The AIHW does not attribute a 'rarity' to neuroendocrine cancer but it has been included in this submission as a rare cancer.

Between 2018 and 2022, NHMRC committed approximately \$221.6 million for 186 new research grants relevant to rare and/or less common cancers. This equates to approximately 5.0% of total NHMRC commitments across the same time period (refer [Attachment A](#), Table 3).

Funding committed for new grants during this period included research into 20 different rare cancer types and seven less common cancer types defined by the AIHW (refer [Attachment A](#), Tables 1 and 2). This includes \$639,750 committed in 2019 for one grant relevant to neuroendocrine cancer.

Commitments for rare cancers (including neuroendocrine cancer) and less common cancers were approximately 2.8% and 2.3%, respectively, of total NHMRC commitments from 2018 to 2022 (refer

¹ <https://www.aihw.gov.au/reports/cancer/cancer-in-australia-2021/summary>



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Attachment A, Table 3), noting that some grants may be attributed to both ‘rare’ and ‘less common’ cancer types.

Commitments for research into rare and/or less common cancers accounted for approximately 25.9% of all cancer research committed by NHMRC between 2018 and 2022. (refer Attachment A, Table 3).

Should other cancer types be of interest to the Select Committee, NHMRC will provide additional funding data on request to support the Select Committee’s inquiry, where these are available.

Conclusion

NHMRC’s major role is in supporting a foundation of health and medical research and training for the improvement of individual and population health. NHMRC is committed to ensuring that its funding program supports the breadth of research needed to address Australia’s current and future health challenges. NHMRC supports the best research across the full spectrum of topics in health and medicine, including rare, less common and neuroendocrine cancers. The NHMRC model is not designed to favour funding for particular types of cancers. NHMRC grants are awarded based on competitive peer review with the best science and most significant research proposals funded based on the available funding allocation. As outlined in this submission, the MREA mainly funds investigator-initiated (‘bottom up’) research where the research question and the experimental approach are determined by the applicant team. By contrast, the Medical Research Future Fund (MRFF) funds priority-driven (‘top down’) research where grant opportunities are offered to address specific issues that align with the MRFF’s Strategy and Priorities, including specific disease areas. Cancer Australia also funds prioritised cancer research through their Priority-driven Collaborative Cancer Research Scheme (NHMRC undertakes initial assessment of applications for this scheme).

If you have any queries or wish to discuss NHMRC’s submission, please contact evaluation@nhmrc.gov.au

Yours sincerely

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National Health and Medical Research Council

25 August 2023